

Assessing the Impact of a Program for Late Surgical Intervention in Early Blind Children

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ABSTRACT

Objective: Many blind children in the developing world are unable to obtain timely treatment due to lack of financial and medical resources. Can public health programs that identify and treat such children several years after the onset of blindness enhance their quality of life? The notion that visual development is subject to an early ‘critical period’ argues against this possibility. However, there are inadequate empirical data from humans on this issue. To address this need, we examined the quality of life of children living in India and who were treated for early-onset blindness (before one year of age), due to cataracts or corneal opacities.

Methods: As part of an ongoing scientific effort named Project Prakash, we screened over 40,000 children in rural northern India to identify those suffering from early onset blindness. They were provided eye surgeries in a tertiary care ophthalmic center in New Delhi. We subsequently surveyed a randomly chosen set of 64 Prakash children, ranging in age from 5 to 22 years, and obtained their responses on a multi-dimensional Quality of Life questionnaire.

Results: Nearly all of the subjects indicated that their quality of life had improved after treatment. Children reported marked enhancement in their mobility, independence and safety, as also in social integration. Surprisingly, we found no significant correlations between quality of life metrics and factors such as age at treatment, gender, time since treatment, and pre- and post-surgery acuity.

Interpretation: A key question for public health policy makers is whether a program of surgical intervention for older blind children is likely to be beneficial, or if the resources are better spent on rehabilitation via vocational training and assistive devices. The marked improvements in quality of life we find in our data strongly argue for the provision of surgical care regardless of a child’s age.

INTRODUCTION

The WHO estimates that there are nearly 39 million people with blindness worldwide [1]. One and a half million are children below the age of 15 years, and nearly 90% of them live in the developing world [1]. Most of these children live in poverty, which contributes significantly to their poor prospects for receiving treatment [2]. Furthermore, the consequences of living with visual impairment in developing countries are much more severe compared to developed countries. Over 50% of blind children die before they reach the age of five [3]. Given these dire statistics, there is an urgent need to provide appropriate interventions to blind children. From a public health policy perspective, it is crucial to define what form the intervention should take. medical care to children with treatable blindness.

For children with conditions like micro-ophthalmos or optic nerve hypoplasia, for which no satisfactory medical procedures currently exist, interventions are constrained to be rehabilitative, with the goal of helping children best adapt to their blindness. However, for causes like congenital cataracts and corneal opacities, the issue is more complex. Surgical procedures for treating these conditions do exist, but their usefulness for children who have suffered several years of blindness since birth is not certain. Whether they will have a beneficial impact on the lives of the treated children is dependent on the answer to an important, and hitherto open, scientific question: Can the human brain learn to interpret visual information from the eyes even several years after birth?

Past research in visual neuroscience with non-human animal subjects suggests that visual deprivation early in life results in permanent deficits in visual functioning and supporting brain mechanisms, leading to the notion that the visual system has a ‘critical period’ for acquiring visual proficiencies [4-8]. The implication of this idea for human development is that children, who have been blind since early in life due to cataracts or other conditions, will not be able to gain functional vision if treated late in childhood. Hence, such treatments will not result in improvements in their quality of life.

Despite the results of previous animal studies, recent work has demonstrated that children treated late in life for blindness can, in fact, develop significant visual proficiencies. Project Prakash is a joint humanitarian and scientific effort to alleviate treatable blindness in the developing world while also studying key questions regarding human brain plasticity and the development of visual functions [9]. Its operations are currently focused on India that has an estimated 200,000 to 700,000 blind children, nearly 40% of whom have preventable or treatable conditions [10-12]. Results from Project Prakash show that after treatment for congenital cataracts, patients are able to acquire proficiency on an array of visual dimensions, ranging from basic functions such as acuity and contrast sensitivity [13, 14] to more complex abilities such as face localization and classification, spatial imagery, and mapping between visual and haptic senses [15-17]. Although

the children do not reach normal levels for basic visual functions, such as acuity and contrast sensitivity, these findings suggest that the visual system and its underlying neural mechanisms do retain enough plasticity to allow for significant improvements, even late in childhood.

This paper focuses on the issue of whether the visual improvement exhibited post-treatment in the laboratory translates into an improved quality of life for these children. The Prakash children and their families typically live in impoverished conditions, harsh rural environments with limited access to basic necessities such as electricity, and many of the children do not have access to education. These challenges are compounded by the handicap of blindness. How does the ability to see, even if vision is not perfect, alter the lives of these children? The goal of this study was to address this question by surveying the children and their families after treatment on multiple dimensions related to the quality of life. The results have bearing on the potential effectiveness of large-scale public health programs designed to proactively identify and treat early-blind children.

METHODS

Participants

Patients who were surgically treated through Project Prakash, either for cataracts or corneal opacities, were eligible for the study. Patients had been blind since one-year of age or earlier as reported by the child's guardian at the time of treatment. Over a period of one year, we contacted and interviewed sixty-four patients and their families. The participants ranged in age from 5 to 22 years at the time of surgery and were interviewed between 7 months and 8 years after treatment. The pre-surgical visual acuity of the participants ranged from light perception to finger counting at a distance of three meters (equivalent to Snellen acuity of 20/400). The participants were residents of states in northern India (Delhi, Rajasthan, Haryana, Uttar Pradesh, and Madhya Pradesh).

Survey and Method

In pilot testing with some of the extant quality of life surveys, such as the National Eye Institute Visual Function Questionnaire [18], we found that several of the questions posed were not appropriate for our unique patient population. For instance, queries regarding how difficult it is to read newspaper print or street signs assume basic literacy, which is generally lacking in our participant pool. In fact, even the concepts of newspapers and street signs are alien in the remote hinterlands of rural India. Similarly, questions regarding the ability to pick out matching clothes or go see movies/plays/sporting events implicitly assume a basic financial capability and access to resources that are almost entirely missing in the rural context of a developing nation. Along the same lines, queries related to driving prowess are meaningless for the Prakash children.

These reasons made it imperative for us to develop a Quality of Life questionnaire that was better suited to the cultural/financial/medical/educational milieu from which our patient population had been drawn. Accordingly, we created the Prakash Quality of Life Survey (see Supplementary Information). The survey comprised four sections: ‘Basic vision and mobility’, ‘Social integration’, ‘Attitudes’ and ‘General’ with five items per section. For each item, participants were asked to give one of three answers: whether there was improvement (+1), no change (0), or worsening (-1) of the described item. We intentionally asked broad questions and simplified the responses to make the survey comprehensible for children while still being able to assess the impact of restored vision on their quality of life.

Surveys were conducted during the summer of 2013 by social workers and outreach coordinators. Interviews were conducted in the local language (Hindi) at a hospital in Delhi or at the patients’ homes, or over the phone. The aggregate survey results were analyzed by totaling the number of points across survey items and across subjects. In order to reduce the possibility of the children or their families giving biased responses because of a sense of obligation, none of the surveys were conducted by members of the medical, nursing or research teams who had worked with the children during their visits to the hospital. Additionally, it was made clear to the families that participation in this survey was entirely voluntary and not a precondition for any further medical care the child might need.

RESULTS

Figure 1 shows aggregated data from the survey. The maximum score possible for each question is 64 (assuming that every survey participant indicates a post-surgical improvement on that question). Similarly, the lowest possible score is -64, and 0 corresponds to no overall change (or as many instances of improvement as worsening). As is evident from the figure, a majority of the subjects experienced an increase in their quality of life following treatment for blindness. A multinomial goodness of fit test was conducted for each question to test whether the measured score was attainable by chance, assuming a null hypothesis that each response category (improvement (+1), no change (0), or worsening (-1)) was equally likely. The score for each question was significantly higher than chance at a level of $p < 0.01$ after Bonferroni correction for multiple tests. The area of most improvement was in the category of “basic vision and mobility.” The five questions that received the lowest scores (41-46 out of 64) were:

- Your ability to watch TV, movies or do other things for enjoyment,
- The number of friends you have,
- Change in overall health after gaining sight,
- Your sense of what you can accomplish when you grow up, and
- Your prospects for financial security.

Figure 2 shows the survey data plotted per subject. The highest score here is 20, corresponding to an improvement on all questions asked. Of the sixty-four patients surveyed, only three experienced no change or a worsening of their quality of life. Two of these subjects had poor acuity after surgery, due to untreatable posterior segment ocular pathologies that could not be detected prior to the cataract surgery. It is likely that this is also the case for the third subject, but it could not be assessed since he had not returned to the hospital for post-surgery follow up.

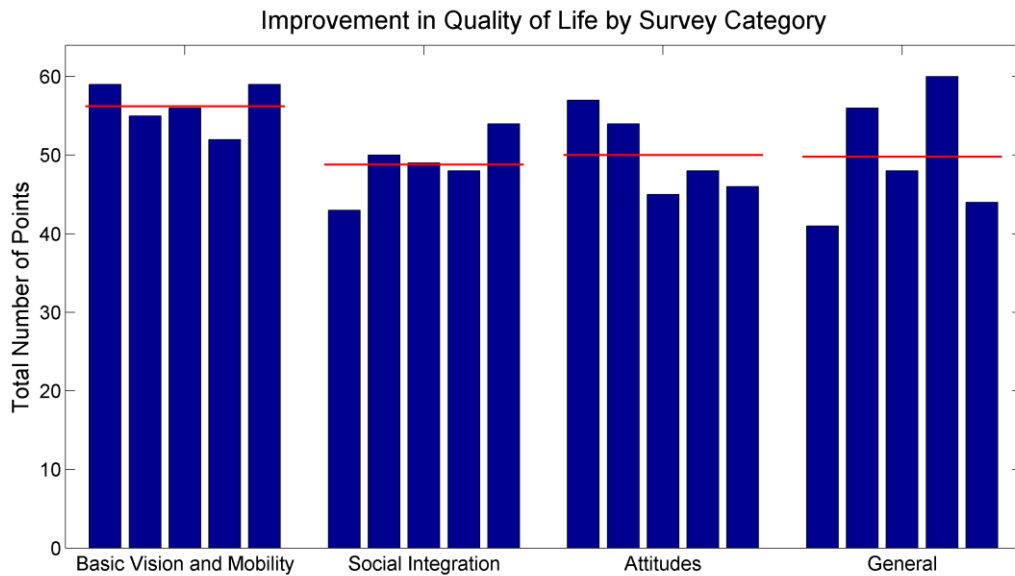


Figure 1. Survey scores totaled across items in the four categories. The red horizontal lines indicate the average score in that category. The specific questions included in each of the four categories are presented as supplementary material.

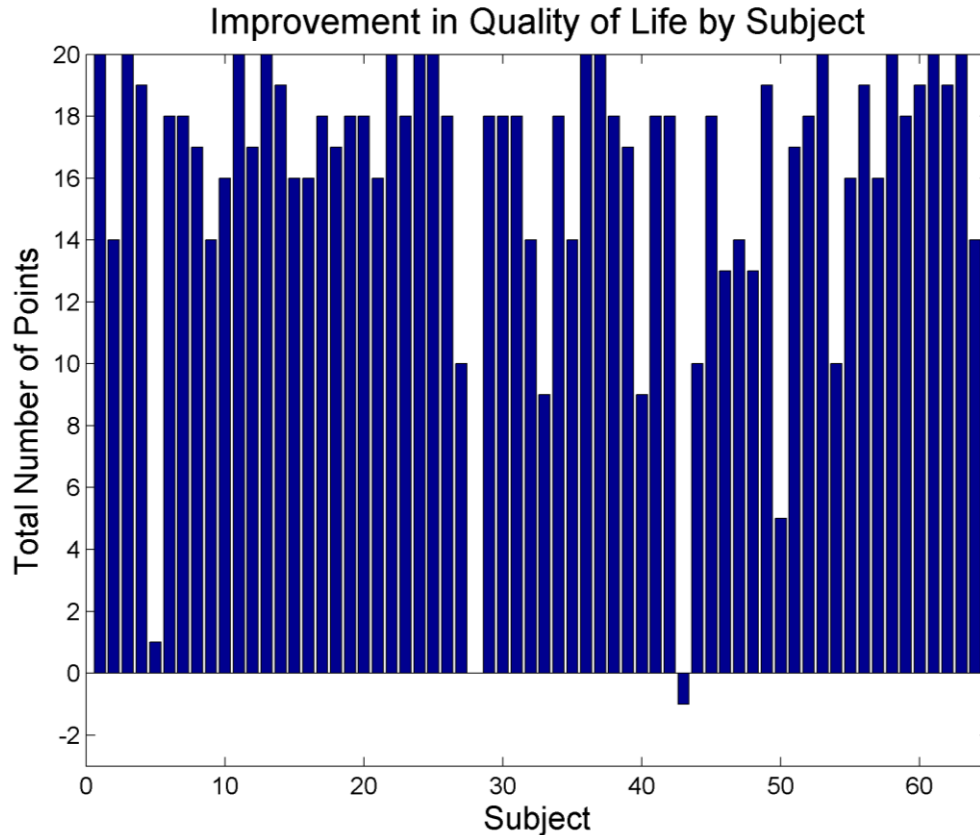


Figure 2. Survey scores totaled across each of the 64 subjects. The maximum score for each subject is 20, corresponding to an improvement across all questions posed in the survey.

We examined variability in the responses to the quality of life survey with respect to: the age at treatment, time since surgery, pre-treatment acuity, post-surgery acuity (n=55 because nine of the patients had not returned to the hospital for post-surgery follow up) and gender of the patients (Figure 3). Spearman rank correlations (age, time since surgery, post-surgery acuity) and Kruskal Wallis one-way analyses of variance (pre-surgery acuity and gender) revealed no significant relationships between these variables and the quality of life scores. There was a trend that better post-surgery acuity was correlated with higher quality of life scores, but this relationship did not reach statistical significance ($\rho = -0.254$, $p = 0.061$).

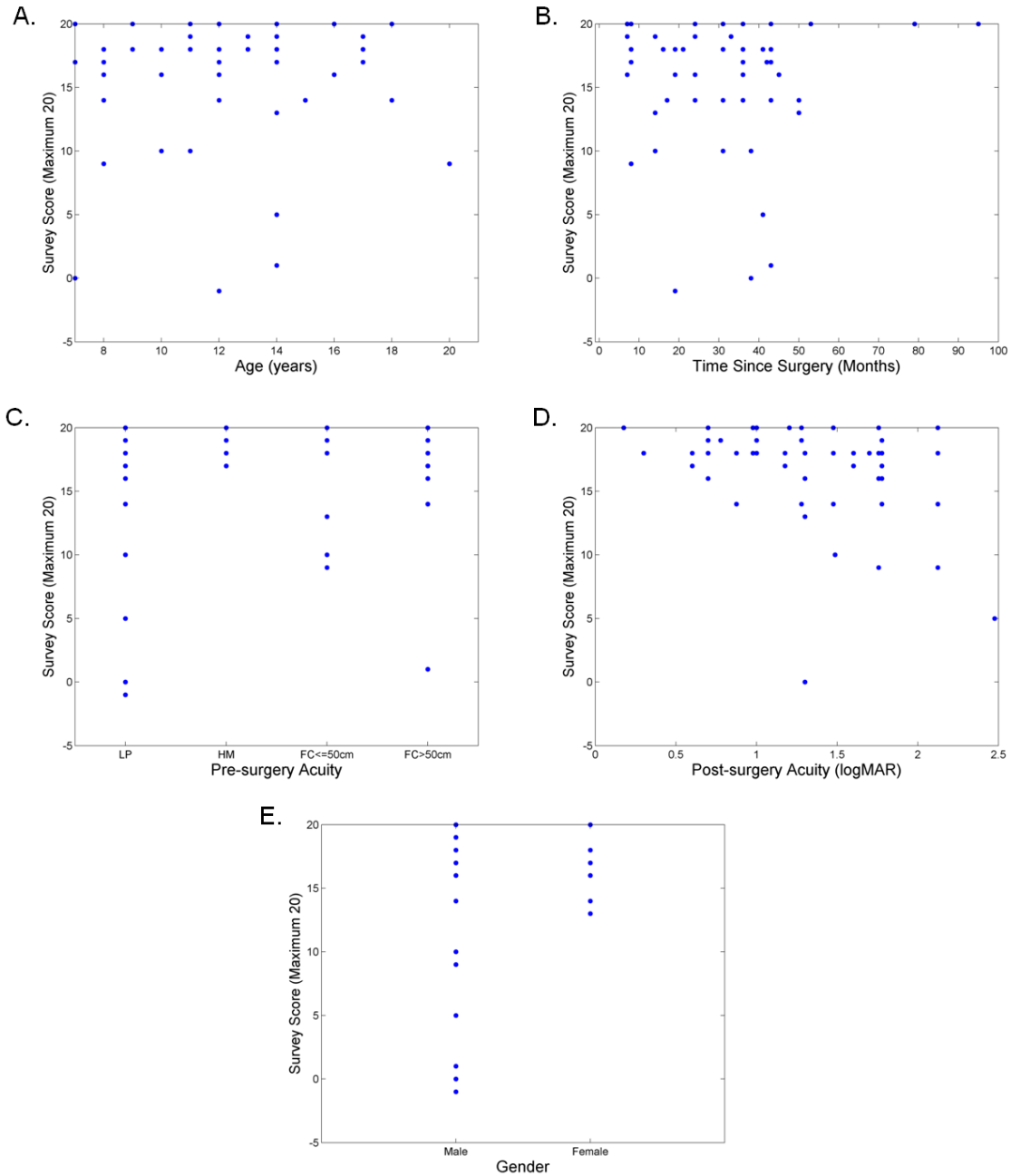


Figure 3. Survey scores plotted against (a) the age of the subject at treatment, (b) time since surgery, (c) pre-surgery acuity (LP = light perception, HM = hand movement, FC<=50cm = finger counting at a distance of 50 cm or less, FC>50cm = finger counting at a distance more than 50 cm), (d) post-surgery acuity (logMAR), and (e) gender. Each blue dot represents one subject.

DISCUSSION

The overarching goal of our study was to examine whether a public health program that provides ophthalmic surgeries to early blind children can positively impact their quality of life. Our results

revealed two important findings. First, even though these children had suffered profound visual deprivation for several years beginning at or near birth, treatment in late childhood or even early adulthood had a positive impact on their quality of life. The greatest change reported was in the participants' abilities to use their vision and travel on their own. Positive improvements were also seen in other domains, including social interactions and societal attitudes towards the children and their families. Therefore, treatment for blindness, even at a late age, can result in significant improvements in a child's quality of life. This conclusion is reinforced by data in Figure 3. The observed improvements are not confined to a specific gender, limited by age or even precise pre-/post- acuity status. Instead, they indicate that surgery benefits almost all participants, despite their marked diversity.

Second, although all four dimensions probed by the survey registered improvements, the magnitude of improvement was least for questions related to future prospects for the child. Although their vision is improving, some children and their families do not feel that the child's ability to find employment or be financially secure improved as a result of treatment. Through further interactions with these families, we have learned that several children either remain in blind schools after treatment or do not go to school at all. Many children return to their villages where their families work as day-laborers and where there are few other options for employment. Even though the visual abilities of these patients improve markedly, they are still considered to be visually-impaired, in part because of their below-par acuity [14]. Therefore, the survey results reveal that providing treatment to curably blind children is just a first step to helping them live fulfilling productive lives. The next step towards this goal may be to develop a program that helps bridge the educational gap and gives children access to other resources, such as optical devices, to help them gain the training and skills needed to function independently.

On the methodological front, we also wish to point out that the Prakash Quality of Life Questionnaire that we developed and deployed for this study can prove a useful tool for other researchers working with similar populations in the developing world. The survey is not country specific, does not assume literacy or significant socio-economic status on the part of the respondents and includes only those questions that can be responded to by individuals across a wide age range, spanning young children as well as adults. We are making the survey publicly available for use by all researchers.

In conclusion, the results of our survey revealed that treatment of blindness, even late in childhood, results in an overall improvement in quality of life. However, there are still some domains, such as education and employment, in which extra support is required. These results are especially notable considering previous notions that treatment after an early 'critical' period would not lead to improvement in the visual abilities of blind children. Our data argue instead for public health programs that can provide medical care to all blind children with treatable ocular conditions, irrespective of the age at which they are identified.

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Contributorship Statement

All authors were involved in study design. AK, TG, GC and P Sinha designed the survey, analyzed the data and wrote the manuscript. P Swami, HD, and SB contacted the patients and conducted the interviews. NC and SDG coordinated outreach efforts and logistics associated with conducting the study. P Swami and SS helped with data recording and conducted initial data analyses. P Sharma assessed acuity outcomes and compiled data. SG conducted surgeries and follow up medical assessments. UM provided additional medical expertise and advice regarding study objectives.

Competing Interests

None.

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